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AUTHOR Karan, Orv C.; Gardner, William I.
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ABSTRACT

The paper considers the role of program planners in ensuring community adjustment of deinstitutionalized severely mentally handicapped persons, especially in light of the provisions of the Budget Reconciliation Act of 1981, which provides a waiver authority to states to increase community programs for the deinstitutionalized population. The paper adopts an ecological view in which the interaction of environmental and individual factors is emphasized. Planners are advised to be proactive, that is, to take the initiative in developing more community resources and alternatives. Among system obstacles cited to deinstitutionalization are lack of staff training, staff recruitment and retention, bureaucratic red tape, and negative attitudes. Suggestions are made for preparing for the transition from institution to community, including facilitating supportive interagency relationships. (CL)

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A PROACTIVE PROGRAM PLANNER'S GUIDE TO COMMUNITY SERVICES DEVELOPMENT FROM AN ECOLOGICAL POINT OF VIEW

Orv C. Karan, Ph.D.

and

William I. Gardner, Ph.D.

Research and Training Center in Community Integration
Waisman Center on Mental Retardation
and Human Development
University of Wisconsin
Madison, Wisconsin

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The Budget Reconciliation Act of 1981 (P.L. 97-35) with its waiver provisions could be a significant catalyst for promoting continued deinstitutionalization efforts. How these efforts proceed, however, will be critical in determining the extent and scope of its impact. Rejecting the notion of community transfer readiness based upon individual factors the central theme of this paper is that continuing deinstitutionalization efforts must focus on system factors and the interaction of people with their environments. The agent of change, identified in this paper as the proactive program planner, must address system factors which have been shown to have both direct and indirect effects on community adjustment processes. This paper identifies a number of these factors and offers suggestions for remediation.

> "The future of deinstitutionalization will be determined more by the ability and willingness of the prospective shapers and policy makers to adapt the community based service system to today's needs than it will be by the extent of the needs of today's populations" (Best-Sigford, Bruininks, Lakin, Hill, & Heal, 1982, p. 139).

There are approximately 130,000 mentally retarded or other developmentally disabled persons living in public institutions (Janicki, Mayeda, and Epple, 1983), the majority of whom are either severely or profoundly retarded (Best-Sigford, et al., 1982), with over 60% at all mental retardation levels exhibiting frequent maladaptive behaviors (Bell, 1976; Vittelo, Atthowe, & Cadwell, 1983). There is also evidence of a declining trend in discharges (Scheerenberger, 1978) and a growing trend in readmissions (Conroy, 1977) resulting in what some now refer to as a "residual population" acculmulating in institutions (Eyman & Borthwick, 1980). Given the current fiscal climate and the inertia of the deinstitutionalization pendulum one might reasonably predict, all else being equal, that there would be little significant movement out of public institutions in the immediate future.

But, all else is not remaining equal. The Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35) could shift the momentum toward more community opportunities for more institutionalized persons. The Act has one important feature known as the Home and Community Based Care Waiver Authority (Section 2176) that adds a provision to Title XIX of the Social Security Act (Section 1915c) granting the Secretary of Health and Human Services the authority to waive existing statutory requirements in order to permit states to finance non-institutional long term care services for Medicaid eligible persons who otherwise would require care in Title XIX certified institutions (Greenberg, Schmitz, & Lakin, 1983). In other words, the waiver means a new source of community funds.

The waiver's impact will vary of course depending on each State's community resources and initiative before it was even an option. In Wisconsin, for example, at the time of its waiver application, nearly 75% of its public funds for services to people with developmental disabilities went toward institutional forms of care, the majority going for services within Wisconsin's institutions for the developmentally disabled (Wisconsin Division of Community Services, 1982).

Generally speaking, one might expect that states which have not distinguished themselves in the deinstitutionalization movement would begin showing more community transfers. This should be true particularly for those institutional residents who would have been transferred earlier had there been community outlets available (Bock & Joyner, 1983).

Those states which have been community service leaders, on the other hand, might be looked to for more innovative attempts at developing community options on behalf of their most severely handicapped institutionalized residents such as their medically fragile; their profoundly and multiply handicapped; and their behaviorally disordered.

Basic Premises

The positions presented in this paper are based on two basic premises. The first is that the waiver authority offers a realistic chance for States to increase their community options for developmentally disabled persons. This in turn will simultaneously reduce the number of those still residing in public institutions.

To accomplish this will require a conceptual shift in conventional practices and procedures. The second premise therefore is that as deinstitutionalization efforts continue, the focus of change and energy must

not simply be at the individual level but rather at the organizational, institutional, community, and society levels (Martin & Laidlaw, 1980). By better understanding these systems and how they impact on individuals we may be able to better shape alternatives for those who do not fit rather than trying to continually force them into the existing limited options that have been developed (Rapport, 1977).

The waiver authority can be a catalyst for such change. In the remainder of this paper the label "proactive planner" will be used to refer to the agent of system changes responsible for anticipating system problems and planning ways to solve these or at least to minimize their impact.

The following sections will include a brief review of the current community services system highlighting its reactive and often misfitting nature. Following this some of the basic components of behavioral ecology will be described since this orientation seems to be well suited to helping conceptualize and design community programs. And, finally, by drawing from current research, system obstacles will be identified and suggestions for improvement will be offered.

Current Community System

Generally speaking community services appear to be best suited for mentally retarded persons who fit in relatively easily without requiring too many environmental, programmatic, or personal modifications. During the initial wave of deinstitutionalization most of those discharged into the community remained (Aanes & Moen, 1976). However, recidivism rates of 50% and higher are now being reported (Sutter, Mayeda, Call, Yanagi, & Yee, 1980).

As the population in the institutions began changing the community services sytem did not and discrepancies between resident needs and services

are now becomming more apparent (Polivka, Marvin, Brown, & Polivka, 1979). Mismatches between recently discharged mentally retarded persons, or those about to be discharged, and their community environments have resulted in a tendancy to "blame the victim" (Ryan, 1971). Thus, institutional programs are encouraged to set higher standards for exit and to not initiate community placement until their residents either acquire higher levels of cognitive and adaptive functioning (Vittelow, Atthowe, & Cadwell, 1983) or until their behavior problems have been modified (Intagliata & Willer, 1982; Sutter, Mayeda, Call, Yanagi, & Yee, 1980; Eyman & Call, 1977). At the same time, group home developers and agency directors complain about the unsuitability of those referred to their programs (Berdiansky & Parker, 1977; Intagliata, Krause, & Willer, 1980).

Novak (1982) believes this type of thinking has contributed to a "myth-of-unplaceability," i.e., a belief that individuals are considered unplaceable when in actuality the situation is that no immediate placement is available outside the institution.

Ecological Issues

Although community failure or inaccessibility is often attributed to the mentally retarded person, there is growing recognition that community placement failures are associated with adverse environmental factors and the interaction of these with resident factors (Landesman-Dwyer, 1981; Siegelman, Novak, Heal, & Switzky, 1980; Willer & Intagliata, 1981). It has even been suggested that most obstacles to community placement are related to service system characteristics as evidenced by short falls in needed services, particularly in the psychological and mental health areas (Jacobson & Schwartz, 1983).

These viewpoints flow from an ecological framework and its person-environmental applications known as behavioral ecology. Behavioral ecology attributes problems to transactions between persons and their settings rather than to causes rooted exclusively within the individuals or environments. It is an evolving orientation represented not by a single theory or series of specific practices but rather as a general set of assumptions, principles, and values. A major premise of ecology is that environments are characterized by the demands they make on individuals and the resources they provide. Ecology is concerned with maximizing the fit and reducing the discord between people and their environments. Behavioral ecological interventions attempt to enhance individual's coping and mastery skills and/or to enhance organizational and community strengths so that the quality of people's lives is improved. Interventions can be at the individual level, the environmental level, or at the systems level. All interventions, however, are characterized by a commitment to evaluation in order to maintain community accountability (Jeger and Slotnick, 1982).

An ecological perspective immediately recognizes the futility in attempting to improve a person's behavioral, cognitive, and adaptive functioning as a condition for institutional release since not only is it possible that such changes could occur naturally within an appropriate community context (Schroeder and Henes, 1978), but the institutional environment itself may be perpetuating and promoting the very behaviors that prevent the individual from being recommended for discharge.

Ultimately, the success of community services for mentally retarded persons will hinge in large part on the adequacy of support systems both formal and informal that can be mobilized on their behalf (Gottlieb, 1983).

This may very well be the major challenge of the 80's, but it is not the defining characteristic of many of today's services. For example, although it has been repeatedly demonstrated that staff behaviors and interaction styles are powerful influences on resident behaviors (Mayhew, Enyart, & Anderson, 1978; Schinke & Landesman-Dwyer, 1981) the social interactions between staff and residents remain low (Landesman-Dwyer, Sackett, & Kleiman, 1980; Reuder, Archer, Dunn, & White, 1980; Repp, Barton, & Gottlieb, 1983).

Social support can cushion stressful life events but, access to social support depends in part on possessing the minimal social skills necessary to develop and maintain positive human relationships. Those who have poorly developed social skills or behavior patterns which generate negative emotional reactions from others may repel rather than attract social interaction (Karan, 1983). This may in turn result in the gradual physical and/or emotional withdrawal of significant others and diminished support for the individual. From an ecological point of view, one of the major reasons social interactions are so consistently low may be due to a lack of reciprocity among participants. If so, program planning must include an assessment of the social interaction processes between mentally retarded persons and the significant persons in their environments so remedial methods could be developed as needed for mobilizing social supports.

It appears as if the duration of resident-staff social behavior is related to various kinds of behaviors of residents (Carsrud, Carsrud, Henderson, Alisch, & Fowler, 1979) with those who are more developmentally advanced garnering more social and care giving behavior from available adults (Reuder et al., 1980). Such findings have serious implications considering that those still in institutional facilities are predominately severely/profoundly

mentally retarded and/or behaviorally disordered. Consistent with this, Reuder et al. (1980) recommend that habilitation of severely and profoundly retarded persons at low developmental levels among other things should be geared to teaching them how to become more effective at gaining caregiver attention.

A Philosophical Shift

> "If you treat people as they are they will remain as they are but if you treat them as they could or should be they will become as they could or should be" (Goethe, 795 A.D.).

The practical application of this philosophical tenet, although desirable, has not been sufficient to lead to meaningful life changes for persons still institutionalized. An ecologically modified version of this position, however, provides a guiding framework for future deinstitutionalization practices.

> Thus, "If you treat people as they are they will remain as they are, but if you treat them as they could be or should be by creating opportunities for them to participate in normal life experiences; by teaching appropriate skills and behaviors relevant to these experiences; and by providing continuing support as needed so as to resolve immediate and potential problems they will begin to become what they ought to be and could be."

"Creating opportunities" is a key element (Best-Sigford et al., 1982) and represents a logical extension of ecological principles. Ecological studies to date have been either represented by attempts to assess both the physical and psychosocial characteristics of existing environments or by attempts to use the social contexts of such environments for identifying the functional skills needed to succeed in such settings (Rusch & Mithaug, 1982). But, unless more community opportunities are created we might be lulled into only becoming better at fitting individuals into existing environments. More

community opportunities mean more environments to assess; more contexts from which to develop functional curricula; more choices; and ultimately better matches between more people and more environments.

There have been many impressive demonstrations to date in which mentally retarded persons have revealed their capabilities to an extent greater than would be normally expected. As examples, Wehman (1980) has shown that mildly and moderately retarded persons are able to sustain competitive employment. Bellamy and his associates (Bellamy, Peterson, & Close, 1975; Bellamy, Inman, & Yeates, 1978) have shown that severely retarded persons can attain productivity levels comparable to those observed in industry while earning non-trivial incomes. And, Karan (1981) has demonstrated that community life for profoundly retarded and multiply handicapped persons is not only possible but desirable. It is interesting to speculate where the participants in these projects would be today and what would they be doing if the opportunities, training, and support necessary for demonstrating their capabilities had not been provided.

The remainder of this paper is an attempt to provide direction and recommendations for the proactive community program developer. Rather than continuing current practices by waiting for institutionalized residents to become "community ready" the primary recommendation is to create more community opportunites for them now. The Budget Reconciliation Act of 1981 with its waiver provisions will hopefully be the catalyst for doing this. What follows are factors that have been shown to be associated with community program failures and problems. The proactive program developer should view these as potential obstacles that must be addressed and corrected in some

way if community opportunities for more mentally retarded persons are to be successfully expanded.

System Obstacles and Concerns

Staff Training

Satisfactory training opportunities for staff have been repeatedly identified as major problems (Berdiansky & Parker, 1977; Bruininks, Kudla, Wieck, & Bauber, 1980; Seltzer, 1981). Few ongoing pre-service training programs exist to adequately prepare direct personnel for the multiple responsibilities of their positions (Handley & Berman, 1979). To date, direct care personnel as a group receive little entry level, function specific training for their critically important positions. In fact, it has been estimated that anywhere from 70-90% of all those who have direct care responsibilities for mentally retarded persons have never had any formal training (Bilovsky & Matson, 1977; Schalock, Harper, & Genung, 1981). This is a condition which must obviously be remediated.

Tender loving care and a general concern or interest in mental retardation are insufficient. Direct care personnel must be capable of creating psychosocial environments in which growth and problem solving can occur (Willer & Intagliata, 1981); they must know how to manage behavior problems (Sutter, 1980); they must know how to form important and warm but not dependent relationships (Siegelman, Novak, Heal, & Switzky, 1980; & Hull & Thompson, 1980); they must serve as trainers to teach new and useful community skills and behaviors; they must be involved in the daily stream of their residents' behavior (Bjaanes & Butler, 1974); they must play a central role in seeking out appropriate services and activities (Siegelman et al., 1980); they

must maintain the health of their residents, and they must create a comfortable and stable setting that respects the human dignity and self-worth of those who are in it (Siegelman et al., 1980).

The community and technical colleges have not been used to sufficient advantage to offer specific training that could begin filling many of the existing in-service and pre-service training gaps. Proactive program planners should attempt to stimulate such activities.

Attracting and Maintaining Staff

The ability to attract competent staff members and to retain them is going to require better pay and working conditions (Zaharia & Baumeister, 1978). Salary and benefit discrepancies between those who work for public facilities and those who perform similar jobs for private non-profit organizations can no longer be justified. Pay differentials of fifty cents per hour less on the average between these two groups of employees have been reported (Lakin, Bruininks, Hill, & Hauber, 1982). In addition, staff need free time; support; encouragement; and respite. These should be well thought out and available (Siegelman, et al.,1980).

There is also what has been referred to as a "critical employment period" (Zaharia & Baumeister, 1978). The likelihood of an individual remaining with the organization depends on successfully passing through this period. To date it has been shown that better educated persons who have had more health related training and past experiences with mentally retarded persons (Siegelman, 1980) as well as those working in organizations that have been in business for some time (Lakin et al., 1982) are the most likely to make it through this critical period. Clear expectations among administrators

(Jacobsen and Schwartz, 1983) and staff (Seltzer, 1981) have also been found to be helpful.

Cutting the Red Tape

The proactive program developer should work with state licensing agents and other bureaucrats so as to streamline standards, improve communication, and promote education (Berdiansky and Parker, 1977). It would also be appropriate to work directly with local government and local housing authorities so as to pool resources and develop joint housing/services programs (Greenberg, Schmitz, & Lakin, 1983).

Increased Access to Adequate Resources

Access to, and the adequacy of, resources and support services are critical to successful community adjustment (Seltzer, 1981; Schalock & Harper, 1978; Martin & Laidlaw, 1980; Polivka et al., 1979). Not only should this include the creation or promotion of more socially integrated vocational, educational, recreational, and social activities (Hall & Thompson, 1980; Edgerton & Bercovic, 1976) but also must include better use of generic services. Access to community health systems, for example, needs to be better developed. Simultaneously, physicians, psychologists, dentists, law enforcement officials, and others must be sensitized to the special needs and conditions of deinstitutionalized people. This should include exposure and training at both the pre-service and in-service levels.

Encouraging and Maintaining Competetent Community Behaviors

The mere location and proximity of where one lives in terms of obtaining appropriate services and behaving appropriately is much more complicated than just the geographical location of the setting (Eyman, Demains, & Lei, 1979).

No assumptions should be made about one's competence until it has been demonstrated under natural conditions in the community. Considering that those who are most proficient are also often the most likely to be returned to the institution (Intagliata & Willer, 1982; Sutter, 1980; Sutter et al., 1980), it just may be that too many false assumptions are made about their capabilities in unsupervised situations and settings.

In planning for successful community integration proactive program planners would do well to remember Edgerton's (1967) advice, e.g. "It would not be an exaggeration to conclude that in general, the ex-patient succeeds in his efforts to sustain a life in the community only as well as he succeeds in locating and holding a benefactor" (p.204). The importance of each benefactor's relationship was that of promoting an environment essential to encouraging and maintaining competent behaviors. Edgerton's recent follow up of his earlier study further revealed that over time as individuals became better able to handle their own problems the benefactors played less important roles.(Edgerton & Bercovici, 1976).

Presence of Others in the Setting

Often there is a tendency to segregate individuals placing those with many skills together and those with fewer skills or behavior problems with others like themselves. Yet, research suggests that the greater the proportion of heterogeneous individuals the higher the overall sociability of the setting. Thus, the social integration of mentally retarded adults of varying levels and behaviors may have beneficial consequences for all concerned (Roemer & Berkson, 1980b).

Proactive planners should also be aware that homes in which additional family members lived tended to have higher failure rates than homes in which there were no relatives other than immediate families (Sutter, 1980). Homes which had lower failure rates tended to have more relatives living nearby than did homes with high failure rates. The perceived neglect by other family members in the home may result in so much family disharmony that the mentally retarded resident will be discharged.

Size of the Setting

Contrary to popular opinion it appears as if the size of the setting does play a role in helping facilitate interpersonal relationships among its residents, but this role is in an opposite direction than what is usually advocated. It has been shown that residents in large group homes engage in more social behavior; interact with more peers; were more likely to have a best friend; and spend more time with their best friends than do residents in small group homes. The smallest facilities do not necessarily foster better interpersonal relationships than do the larger facilities (Landesman-Dwyer, Sackett, & Kleiman, 1980). Careful consideration of social networks and/or moving friends together should be serious considerations when moves to small facilities are contemplated (Roemer & Berkson, 1980b).

Attitudes

Novak (1982) found that if institutional staff have negative perceptions of their resident's placeability the chances they will recommend that person for placement are low. However, she concluded that the placement and success of individuals depended not on the degree of their handicap but rather on what providers were willing and able to provide.

It has also been shown repeatedly that community resistence can be a substantial stumbling block towards the development of community residential facilities. More positive attitudes will be found among individuals who want contact with or who already had some kind of previous exposure to the mentally retarded (Kastner, Reppucci, & Pezzoli, 1979). One of the implications from this is to promote as much public exposure to the mentally retarded as possible. There are also those who believe (Siegelman, 1976) that somewhere between the inner city slums and the plush suburbs there is room for the realistic planner to operate, selecting a site to optimize program success without worrying about attitudes.

Preparing for Transition from the Institution to the Community

Common sense suggests that individuals will react to changes in familiar routines particularly when these include different living arrangements, activities, and people. This reaction, referred to as either transitional shock (Coffman and Harris, 1980) or relocation stress or syndrome (Heller, 1982), may include depression, emotional behaviors, acting out, general disorientation, illness, and even death.

If it occurs relocation stress generally lasts about four to six weeks (Heller, 1982) but, transition often includes a latency or honeymoon period lasting several weeks preceeding the emergence of the stress reactions (Coffman & Harris, 1980).

Based on recent findings one should expect lower functioning residents, on the average, to show behavioral gains in response to the relocation while higher functioning residents are more likely to show a pattern of withdrawal and generally decreased behavioral output (Cohen, Conroy, Fraser, Snelbecker,

& Spreat, 1977). This is one of the risks of relocation but tends to be of a short term nature. Additionally, it has been shown that those who have displayed some degree of emotional instability or lability in the past are those most likely to be effected by relocation (Cochran, Sran, & Varano, 1977).

Generally speaking institutional and community programs exist as if they were in two separate worlds (Karan, 1981b). For example, Novak (1982) found that community administrative staff had little or no knowledge about particular institutional residents from their community who had been recommended for placement, even in those cases where they had been on a placement list for years. The proactive planner should initiate steps that will: (1) insure that programmatic staff from both the institution and the community are aware of each others' programs and, (2) begin cooperative planning.

The content of resident training in institutions should be based upon that which will be expected in the community, and the full range of social and physical environments that will impact on and be affected by trainees must be considered (Rusch and Mithaug, 1982).

Once in the community residents spend significant portions of their day with a variety of individuals in different settings. It is therefore important for the proactive planner to facilitate supportive interagency relationships since the immediate settings within which people spend their time exert a considerable amount of power over their behavior (Berkson & Landesman-Dwyer, 1977; Roeme & Berkson, 1980a). To this extent,distorted or noncooperative working relationships between and among agencies can be a significant obstacle to successful community adjustment (Bruininks, Kudla, Wieck, & Hauber, 1980).

When institutional transfer is planned the likelihood of relocation syndrome can be reduced by: (1) involving multiple levels of staff both from the community and from the institution (Weinstock, Wulkan, Colon, Coleman, & Goncalves, 1979; Cochran et al., 1977); (2) arranging site visits to the new settings (Weinstock et al., 1979; Cochran et al, 1977); (3) to the extent possible involving the resident in the preparation for the move (Weinstock et al., 1979; Cochran et al, 1977); (4) involving the family in the planning (Weinstock et al., 1979; Cochran et al, 1977); and (5) involving a personal advocate (Martin & Laidlaw, 1980; Cochran et al, 1977; and Edgerton, 1967).

The transition itself should occur gradually (Martin & Laidlaw, 1980; Karan, 1981b). Since moving into the community at a minimum usually requires adjusting to two totally different environments simultaneously, e.g., a day program as well as a place to live, arrangements that reduce the adjustment process to only one new environment at a time have been shown to decrease the transitional shock (Karan, 1981a).

Additional considerations for reducing relocation syndrome include retaining staff who transfer with the individual, although it has also been shown that when familiar staff are replaced with more competent staff this also reduces relocation syndrome (Heller, 1982). Further there are important social networks which develop over time in institutional settings and these may work positively to reduce the stress of the transition. As previously mentioned, perhaps rather than transfering individuals separately, transferring friends together may lessen the shock for all (Roemer & Berkson, 1980b). Finally smaller staff-to-client ratios within the immediate period following relocation are recommended (Schalock, Harper, & Genung, 1981).

One should not forget that the transferring resident is not the only one who may experience stress or crisis . It has been shown that almost 50% of the families experience some type of crisis at the time of discharge (Willer, Intagliata, & Atkinson, 1981). The family's role is critical in the transition process (Schalock, Harper, & Genung, 1981) and proactive program planners must be able to realistically and honestly respond to family concerns over the security and stability of the community placement since these issues are of major importance to many of the parents of persons still in institutions (Payne, 1976).

Summary

Research cannot yet account for the reasons why among similar individuals some succeed in the community and others do not but there are strong indications that person and setting characteristics do interact and influence placement outcomes (Intagliata & Willer, 1982). With the impetus of the Budget Reconciliation Act of 1981 and its waiver authority, proactive planners may begin seriously considering community options for a greater number of severely handicapped mentally retarded persons than perhaps at any other time. Program planners should no longer simply sit back and wait for those now living in institutions to show us they are "community ready". Rather, it is time to be proactive and take the initiative to develop more community resources and alternatives. Identifying the strengths and deficiencies of these and attempting to minimize obstacles inherent in the systems within which they are located is an appropriate direction that will ultimately contribute to better matches between more mentally retarded people and their community settings.

Whatever programs, facilities, or services are developed, however, should have a sound evaluation technology. These should include such things as measurements of the person's satisfaction, periodic determinations of the person's level of functioning, assessment of significant others' satisfaction with the settings, analyses of the residential and psychosocial climates, the estimation of approximation of normalization, and measurements of the costs involved (Martin & Laidlaw, 1980).

It is also important to recognize that an individual's social adjustment may flutuate markedly not only from year-to-year but in some cases month-to-month, week-to-week (Edgerton, 1976) and, among the seriously behaviorally disordered even from day-to-day. Perhaps these fluctations represent the individual's way of telling us that their ecological systems are out of balance and that the environmental demands on them and their available resources for meeting these demands are not sufficient at that particular time. If adjustment problems are conceptualized from this viewpoint perhaps we can broaden our field of vision beyond simply the individual, and also identify contributing environmental and/or systems obstacles. Once done, remedial steps to alleviate these obstacles should be taken so as to shift the balance in a more equitable direction that includes both individuals and their community environments.

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